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ABSTRACT

The document offers guidelines effectively monitoring the quality of care provided in community residences serving people with disabilities. An initial section offers suggestions on observation and evaluation procedures. The remainder of the document lists possible questions to be asked in 19 areas: location, building and yard, relations with the neighborhood, admission, operation, interior, habilitation and treatment, staff, residents, staff/resident communication, vocabulary, daily routines, clothing, personal appearance and hygiene, personal possessions, resident's rights, control, relations with family members, and records. (SBH)

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OBSERVING COMMUNITY RESIDENCES

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INTRODUCTION

In 1972, the Center on Human Policy first published Observing in Institutions, a guide to touring state schools and mental hospitals. Dramatic changes have occurred in residential services for people with disabilities since that time. Spurred by federal and state laws, progressive federal court decisions, and consumer activism, many state systems have embraced the goal of deinstitutionalization. Thus, in the past decade, there has been a gradual, but consistent, movement in the direction of serving people with disabilities in community based settings, known variously as "group homes," "halfway houses," and "community residences."

Of course, deinstitutionalization has not proceeded smoothly in all cases. To the contrary, in some, perhaps most, states, deinstitutionalization has resulted in "dumping" and "reinstitutionalization"; that is, in moving people from large, public institutions to small, private ones or from custodial care facilities to non-care ones. For this reason, there remains a need for vigorous advocacy and monitoring efforts on behalf of persons in institutions and community settings alike. We have prepared this guide to enable consumers and citizens to more effectively monitor the quality of care provided in community residences serving people with disabilities.

THE QUESTIONS

Observers may wish to carry this guide with them during their first days "in the field;" however, we would advise against this approach. Admittedly, we wrote this guide hoping that readers would be able to use it to move beyond the limitations imposed during official guided tours as well as beyond those we all experience when observing something new. Yet we would warn against the use of this manual as a tour-book. The best way to find out about a setting is to listen to people who work and live there and to observe the normal, everyday activities as they occur. After just listening and observing, you will find that many of the questions will be answered without ever having actually been asked. At times you may want residents or staff in the residence to speak about certain aspects of daily life. In such instances, it would be advisable to rephrase the questions more casually and informally in an attempt to elicit natural, unguarded responses. For example, instead of saying, "How would you characterize life in this residence?" you might ask, "What's this place like?"

Quite obviously, this booklet does not contain all possible questions one might wish to ask about a facility, although we have attempted to make it comprehensive. Some questions may not be applicable to certain residences, while some settings will probably call forth additional questions from the observer. Readers should maintain a certain amount of flexibility and not allow this booklet to become a rigid substitute for their eyes and ears.

EVALUATION

Many people who observe in service settings may want to do more than "understand" what they are observing; they may want to evaluate as well. Our only warning in this regard is that an effort be made to separate what you see from your judgment about it. That is not to say that one should not evaluate the residence. However, it is often easy to confuse factual events and circumstances with opinions and feelings one brings to the setting.

With that warning in mind, let us consider the evaluation process. Whenever we begin to evaluate what we observe, we are in effect leaving the realm of factual observation and entering an area of judgment; this raises the issue of what evaluative criteria to apply to community residences. Everyone will have to arrive at his or her own criteria for judgment and, in each case, the criteria will be a function of individual morality and belief. Our personal criteria for evaluating any setting are tied to the concept of "normalization," which, to paraphrase Bengt Nirje, refers to the practice of making jobs, residences, educational programs, and other services available to people with disabilities in a manner that conforms as closely as possible to the norms and patterns of the mainstream of society. One way of testing a community residence by the "normalization" criterion is to simply ask: "Are residents being treated in the same manner that I am used to being treated?"

ADDITIONAL HINTS ON OBSERVING

People who work in any organization have the tendency to put their best face forward. Visitors are often shown the new programs, the most modern facilities and, in general, the more pleasant and exemplary aspects of the setting. Keep this in mind when you visit the residence.

Most people who visit community residences spend only a few hours in the setting. If you intend to develop a feeling for life at the residence, you will probably want to spend more time than this "in the field." You will probably want to engage in casual conversation with residents and staff alike as well as to observe day-to-day activities. You may want to observe at night, as well as during the day.

As you proceed with your observations, you may become confused by the many different "messages" or "perspectives" communicated to you by residents and staff. It is important to mingle with all the people in the residence so that you are exposed to an overview. To talk only to the administrator is to ignore all other facets of the setting. As you listen to the various perspectives, you may wish to resolve the confusion by deferring to the person in the highest position of authority. You may want to accept this person's perspective as the "truthful" or "objective" one. This may happen easily since our society expects us to defer to those in command. No matter how confusing the task, you should try to develop a perspective that allows you to treat all views as equally "true." People see things differently, depending upon their position. Your job is to see the world from the point of view of a variety of people. If you wish to draw conclusions about your observations, these should be based on your knowledge of many perspectives rather than one.

People have a tendency to modify their behavior in the presence of strangers and you should take this consideration into account when observing. The degree to which others modify or guard their behavior will depend, in part, on how you, as a stranger, conduct yourself. If you ask threatening questions or phrase your inquiries in such a way as to put people on their guard, they are likely to hold back from engaging in open conversation. If you are snobbish or overly aggressive, people may try to avoid you or provide unrevealing "yes" and "no" answers. Moreover, if staff or residents feel that you might break their confidence by passing on information to people "higher up," they might be reluctant to speak freely. It is therefore best to play down your own position and to conduct yourself in an open and friendly way. Say "hello" or "hi" to people who pass you in the setting, for example, and accept coffee and other such things when offered. Volunteer to help

people with their tasks. Dress in an appropriate way, without over- or under-dressing. Finally, the more time you spend in the field, the more likely you are to gain acceptance by all participants and to begin to understand their many perspectives on life at the residence.

A useful technique for making your observations profitable is to attempt to concentrate as intensely as possible on everything you see and hear. You should pay special attention to comments and conversation, to environmental factors such as architecture and decor, and to activities, so that you do not overlook things which might ordinarily go unnoticed. You should constantly ask yourself, "What does this event, activity or comment reveal about the life in this place?" A helpful way of preserving the quality of your observations is to record them immediately after observing, when you are out of the presence of participants of the setting.

OBSERVING COMMUNITY RESIDENCES

I. Location

Where is the residence located?

Residential neighborhood?

Commercial or industrial neighborhood?

What is the neighborhood like?

Is the neighborhood pleasant and attractive?

Are there other group homes, nursing homes, sheltered workshops, and other service settings in the immediate area surrounding the residence?

Is the neighborhood oversaturated with service settings?

Is the residence accessible to stores, public transportation, parks, etc?

Are there adequate vocational, educational, and supportive services in the community?

II. Building and Yard

What does the residence look like from the outside?

Is it distinguishable from other homes in the neighborhood?

Is the residence in good condition?

Are there signs of conspicuous labels on the outside of the residence?

Is there a yard?

Is it in good condition?

Are there fences or barriers outside of the residence?

III. Relations with the Neighborhood

How do residents and staff get along with the neighbors?

Are residents and staff involved in neighborhood activities?

Do neighbors ever stop by the residence to visit?

Do residents and staff ever visit the neighbors?

How do residents and staff view the neighbors?

How do neighbors view the residence and the people there?

IV. Admission

What are admission procedures like (both official and unofficial)?

Who makes referrals to the facility?

How and by whom are residents brought?

Do residents have to meet any special qualifications to live at the residence?

What?

Is the facility the "least restrictive alternative" for everyone living there?

Do residents move to more independent living situations from the residence?

Do residents ever run away from the facility?

What do staff members think about runaways?

How do staff treat runaways?

What is the average length of stay at the residence?

V. Operation

What agency operates the residence?

Is the agency profitmaking or not-for-profit?

How many other facilities does the agency operate?

Who certifies the agency?

Must the agency meet certain standards?

Who evaluates and monitors the residence?

Does the agency have a board?

Who is on the board? Neighbors? Residents? Other consumers?

Are board members active in the operation of the residence?

How does the agency receive its funding to operate the residence?

Is the funding adequate?

VI. Interior

How many rooms are in the residence?

What rooms are in the residence?

Living room?

Dining room?

Bedrooms?

Bathrooms?

Laundry room?

Recreation room?

Kitchen?

How many residents sleep in each bedroom?

Is the residence clean, attractive, comfortable, and homelike?

Does the residence look any different from the average home?

Is the residence appropriately furnished and decorated?

What is the furniture like? Is it comfortable?

Do the beds have pillows and bedspreads?

Do residents have their own closets and dressers?

Are there curtains, pictures, rugs, and other normalized decorations and furnishings?

Who decides on decorations and furnishings? Residents? Staff? Administrators?

Are residents free to decorate their own living space?

How many feet of floor space do residents have in their rooms?

Does the facility meet fire and safety standards?

Are fire and safety devices inconspicuous?

What is the temperature like?

Are there any noticeable smells in the residence?

Do staff members have their own living space?

VII. Habilitation and Treatment

Does each resident have an individual habilitation plan containing long-term and short-term objectives?

Is this plan developed by qualified staff?

Is the plan reviewed annually?

Are residents and/or their guardians involved in the development of this plan?

Has each resident received a comprehensive social, psychological, educational, and medical evaluation?

How are these evaluations conducted?

Are these evaluations conducted by qualified professionals?

Is there a specific staff member assigned to each resident?

Who is responsible for seeing that the resident is working toward and attaining habilitation goals?

Are residents involved in full-time programming?

Educational and developmental programming?

Occupational therapy?

Physical therapy?

Vocational rehabilitation?

Psychological counseling?

Recreation?

Work Programs?

Where does programming occur?

Do all residents leave the facility during the day to participate in programs or other activities?

Are residents served by professionals (e.g., doctors) in the community as opposed to those from institutions?

Do residents receive training and assistance in acquiring skills necessary for more independent living (e.g., personal hygiene, washing clothes, making beds, cooking, budgeting)?

Do residents have opportunities to be involved in social and leisure time activities alone or in small groups?

Are residents provided with eyeglasses, hearing aids, and prosthetic devices?

What diseases and parasites are common among residents?

How are these treated or controlled?

Are there any overt signs of unattended cuts, sores, or bruises?

Do residents complain about untreated physical ailments?

Do staff members seriously consider residents' complaints about physical illness?

Do residents receive prompt and adequate medical treatment for physical ailments?

Are residents subjected to behavior modification programs which serve staff convenience rather than the good of the resident?

Are noxious or aversive stimuli used in behavior modification programs?

Are these used with the prior knowledge and consent of the resident or guardian?

Are residents used in drug experiments and other research projects without their prior knowledge and/or consent?

Are nonambulatory residents removed from bed during the day?

Are nonambulatory residents provided with physical therapy and a range of motion exercises on a regular basis?

Do nonambulatory residents show signs of neglect or lack of exercise (e.g., bed sores, atrophied limbs)?

Are nonambulatory residents lying on the floor? On mats?

Are they provided with supports or cushions?

How are nonambulatory residents fed?

Are they fed in an upright position?

Are nonambulatory residents provided with individually fitted wheelchairs?

Are physical facilities (e.g., toilets, buildings, water fountains) adapted for people in wheelchairs?

What were residents doing at the time of your visit?

Were they engaged in any meaningful activities?

VIII. Staff

How many staff members work at the facility?

How many live at the residence? How many come in as needed?

What are the various staff positions at the residence?

What are the qualifications for staff?

What training do staff receive?

What is the staff turnover rate?

What do the staff members think of their jobs?

Are staff members primarily concerned with custodial care or habilitation?

How much staff time is taken up by custodial and surveillance activities as opposed to working with residents?

How do staff members view residents?

As developing persons?

As children?

As immoral?

As dangerous?

As victims?

As poor souls?

Do staff refer to adult residents as "kids" or "boys" and "girls"?

Do the staff stereotype the residents (e.g., as "low grades," "chronics," "vegetables")?

IX. Residents

How many residents live at the home?

Is the size of the residence no larger than the average home?

Where did the residents live previously?

How do residents view staff members?

How do residents view the home?

Do they say different things in private than publicly?

X. Staff and Residents: Communication

When do staff members talk to residents?

How do they talk to residents (e.g., commands)?

How do residents talk to the staff members?

Do residents approach staff members more than staff members approach residents?

Do staff members hide things from residents and vice versa?

Do staff members raise their voices when talking with residents?

Are residents ignored by staff members?

To what extent do staff members treat residents as if they are not present?

Do staff members gossip about residents?

Are residents teased? How?

Are residents cursed?

Are residents subjected to verbal indignities or "put downs?"

Do staff members encourage or force residents to perform for visitors?

Do staff members contradict residents when they are speaking?

How do staff members refer to residents?

Do they use first names or last names? Is this reciprocal?

What nicknames do staff use for residents?

How do residents talk among themselves?

XI. Vocabulary

What special names do staff members use for activities, objects, and places at the facility?

To what extent do program titles (e.g., "vocational rehabilitation") actually reflect activities at the facility?

What words or phrases are used which you have not heard before?

Do staff members use an esoteric vocabulary to refer to mundane events and activities?

Can staff members intelligently discuss the vocabulary they use?

Do staff members use cliches when talking about residents (e.g., "Give them an inch and they'll take a mile")?

XII. Daily Routines

Do residents spend time in a number of different settings over the course of the day?

What is the schedule of daily life?

How does this schedule compare with life in the community?

When do residents get up, eat, bathe, and go to sleep?

To what extent are daily routines individualized? Do residents do things en masse?

What is a typical weekday for a resident? Weekend?

What are bathing procedures and facilities like?

How often do residents bathe?

Who determines when residents bathe?

What are mealtimes like?

Is the food appetizing and nutritious?

Do residents have a choice of foods at each meal?

Where do residents eat? What is the atmosphere?

How much time is given for residents to eat?

How is the food served?

What eating utensils do residents use?

How are residents who have difficulty eating treated?

Do staff members eat with residents?

Can residents eat other than at mealtimes?

Is there a place to go for residents to be alone?

Do residents maintain their own living quarters?

What other kinds of work do they do at the residence?

XIII. Clothing

Do residents have their own clothing?

What is this clothing like? Does it look normal?

Is clothing conspicuously marked with people's names?

Do residents select their own clothes to wear?

Are residents' clothes clean?

Are residents kept dressed?

Is outdoor clothing available?

Is there any difference between staff members' clothing and residents' clothing?

XIV. Personal Appearance and Hygiene

What is residents' appearance like?

What are their hair styles? Are these appropriate for their age and sex?

Do residents have control over their appearance and hair styles?

What personal hygiene items are available for residents to use?

Are residents assisted, when appropriate, in grooming and personal hygiene?

Are residents encouraged to learn to do things for themselves?

Is the number of toilets adequate for the number of residents?

Are the bathrooms clean and free of odor?

Is there toilet paper in the bathrooms?

Are there toilet seats on the toilets?

Are there soap and towels in the bathrooms?

Are there stalls with doors around the toilets?

XV. Personal Possessions

Do residents have their own possessions?

Are these appropriate for residents' age and sex?

Do residents have their own personal hygiene articles, toothbrushes, combs, brushes, etc?

Are there magazines, newspapers and books around for residents to read or look at?

Are children provided with toys?

Do residents have their own places to store their possessions?

Do residents have access to their possessions?

XVI. Residents' Rights

Are residents provided with privacy?

Do staff members knock before entering residents' rooms?

Are residents asked if they mind having outsiders visit their residence?

Do residents have their own money and property?

How is their money handled?

Are there any rules concerning mail?

Is mail censored?

Are residents free to make phone calls in private?

Are residents allowed to have visitors of their choice?

Are residents allowed and encouraged to vote?

Do residents have opportunities to interact with members of the opposite sex?

What rules govern sexual activities?

Are residents free to associate with persons of their choice?

Can residents smoke cigarettes and drink alcohol?

Are residents permitted to have matches or lighters?

Are details concerning residents' lives kept confidential?

Can residents practice religion as they choose?

Are residents living in the least restrictive setting possible?

Can residents bring grievances against the facility or the staff?

Are there written grievance procedures?

To what extent do residents govern their own lives?

Do residents have their own decision-making body? How does this work?

Do residents have access to lawyers or to other advocates?

Are residents free to come and go as they choose?

Do you think it would be difficult to maintain your sense of dignity if you were living at the facility?

XVII. Control

What restrictions are placed on residents' freedom of movement within or outside of the facility?

What behavior control techniques are used?

Do staff use some residents to control others?

What physical measures are used to control residents?

What kinds of restraining devices are used?

Straight jackets?

Binding devices?

Shackles?

Helmets?

Mittens?

When are restraining devices used?

What policies govern the use of restraining devices?

Do staff follow these policies?

What percentage of residents receive tranquilizers or other behavior control drugs?

Are residents told what medications they receive?

Are prescriptions written with a termination date?

How often are prescriptions reviewed?

Can residents refuse to receive behavior control drugs?

Are drugs used as a substitute for programming?

Do residents show signs of negative side effects of drugs (listlessness, neurological disorders, anxiety, etc.)?

Do drugs interfere with the resident's habilitation program?

Do residents receive routine checkups for negative side effects of drugs?

Do staff members ever threaten residents?

Are residents coerced into telling information about other residents?

Is residents' past behavior used by staff to humiliate or degrade them?

What behaviors do staff punish?

Which staff members have the authority to punish residents?

Are residents allowed to express themselves without fear of punishment?

Is denial of food ever used as punishment?

Is "therapy" perceived as punishment by residents?

What tasks are used as punishment?

Are residents in danger of assault from other residents?

Is isolation ("time-out") used as a form of punishment?

Are there any locked areas within the residence?

XVIII. Relations with Family Members

Is there communication between the family and residence staff?

What rules apply to visits by family members?

Are family members encouraged to visit residents?

Are family members permitted to visit all areas of the facility?

Are family members consulted in the development of habilitation plans and in other matters regarding residents' care?

XIX. Records

What are residents' records like?

Do records contain a place for residents' grievances?

Do records present a negative view of the resident and his or her capabilities?

Do staff regularly consult residents' records to assure continuity of care?

Are residents' records kept confidential and private?

Do residents and/or their guardians have access to their records?

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